

Spring 2008

The Primary Site is a semi-annual publication of the Wyoming Cancer Surveillance Program (WCSP).

This and previous issues are also available online at:

http://www.health.wyo.gov/phsd/wcsp/news.html

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The Primary Site

Why Does the State's Cancer Registry Collect Follow-Up Information???

Date of Last Contact or Death, Vital Status, Cancer Status, Recurrence, New Primaries, Treatment - what do we do with all this information?

When a Wyoming resident is diagnosed with cancer and it is reported to the Wyoming Cancer Surveillance Program (WCSP), the registrars enter the case into the main database. One year later, the follow-up process begins and will continue yearly for the rest of that person's life. We strive to maintain the most accurate, current and complete data possible. These data are reported yearly to the National Program of Cancer Registries (NPCR) which is administered by the Centers for Disease Control and Prevention (CDC), and to the North American Association of Central Cancer Registries (NAACCR). This makes the statistics useful at the national level, not just county and state.

One organization that uses NPCR data is the National Comprehensive Cancer Control Program. By examining the incidence rates, areas in need of action are chosen. One plan that has been put into action is to help raise awareness to detect breast and cervical cancer earlier and offer screenings to women over 40 with incomes under a certain guideline.

NPCR has studied things like patterns of care that cancer patients receive. In addition, they prepare a yearly cancer incidence and mortality report for the entire United States, which is also broken down by state.

Having current, complete and accurate data allows the possibility of many different epidemiological applications such as cluster, survival and cohort studies. It is even possible to analyze the effectiveness of treatments.

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According to the CDC, "Data collected by state cancer registries help public health professionals understand and address the nation's cancer burden. Vital information about cancer cases and cancer deaths improves health agencies' ability to report on cancer trends, assess the impact of cancer prevention and control efforts, participate in research, and respond to reports of suspected increases in cancer occurrence."

While the gathered follow-up data are primarily used for incidence and mortality statistics at the state level, the potential is there for a multitude of other valuable uses. Thank-you for your assistance with this very important task!

References:

Dr. Joseph Grandpre, epidemiologist, Wyoming Department of Health

www.cdc.gov

www.advanceweb.com/him

Update:

The WCSP was in error in their article "Why all the copies?" that was in "The Primary Site "Fall 2007 issue. In The article it was stated that, "Data elements are collected and submitted to the NCDB by the Wyoming Cancer Surveillance Program using nationally standardized data item and coding standards."

This statement was incorrect. The Wyoming Cancer Surveillance Program (WCSP) submits data the National Program of Cancer Registries (NPCR) as well as the North American Association of Central Cancer Registries (NAACCR). The WCSP does not submit data directly to the National Cancer Data Base.

More than Just Numbers

The Cancer Registries Amendment Act of 1992 established the National Program of Cancer Registries (NPCR) and authorized the Centers of Disease Control and Prevention (CDC) to provide funding, set standards, and required Central Cancer Registries supported by State Laws.

Wyoming's statute W.S. 35-1-240 (b) and P.L. 102-515 provides a foundation for the Wyoming Cancer Surveillance Program (Central Registry) and assures that the data can legally be collected and made available for program planning, evaluation and research.

The Wyoming Cancer Surveillance Program receives casefinding and abstracting from hospitals. But the registry is responsible for casefinding at other sources for cancer diagnostic or treatment information including hospital disease indices, pathology labs, doctors' offices, and death certificates to insure case completeness.

A complete case identifies the patient, the disease, the cancer-directed treatment and the disease process from the time of diagnosis until the patient's death.

So, why do Tumor Registries need all of the information?

The information gathered is the foundation for Cancer research, treatment advances and prevention. In the goal to analysis data, prevent and control cancer and improve care for patients, the registries provide evidence-based information to physicians, scientists, clinicians, health officials and others to assess the effectiveness of various diagnostic trends, treatment methods, and cancer control initiatives.

Cancer registries are the essential links between cancer care and rational cancer control.

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Do You Know HIPAA?

The Health Insurance Portability and Accountability Act (HIPAA) was passed by congress in 1996 to set a national standard for electronic transfers of health data. At the same time, congress saw the need to address growing public concern about privacy and security of personal health data. The Privacy Rule was effective on April 14, 2003 for most health care providers, health plans and health care clearinghouses. If you expect HIPAA to restore your confidence that sensitive medical data is a matter between you and your doctor, you will be disappointed. HIPAA sets the **standard** for privacy in the electronic age where health industry, government and public interests often prevail over the patient's desire for confidentiality

Before HIPAA, your right to privacy of health information varied depending on what state you live in. Now, HIPAA set the basic standard by which all states health care services must abide. There are also existing state laws that pre-exist HIPAA. These laws are used to collect health information independently and are not acting as health plans and therefore are not covered by the HIPAA Privacy Rule.

It is important to remember that HIPAA only applies to health care services. Other service industries may adopt a privacy policy for their customers, what they will or will not disclose is up to them, but it is not and cannot be referred to as a HIPAA privacy rule. HI-PAA applies to three fundamental types of organizations: Health Plans (insurances), Health Care Clearinghouses (billing services, transcription services) and Health Care Providers (physicians, dentists, pharmacists, hospitals). If an agency does not pay for healthcare, provide healthcare or process healthcare information, they are not considered covered by HIPAA. That would include Workers Compensation programs, Government programs that fund health care through grants and Government oversight agencies.

The HIPAA Privacy Rule is misunderstood, because very few people have taken time to investigate the true meaning of the act. Did you know: no consent is ne-

cessary for one doctor's office to transfer a patient's medical records to another doctor's office for treatment purposes? Email may be used to communicate with patients and doctors/healthcare providers as long as adequate safeguards are used. If the patient does not object, a health care provider may disclose medical information to the patient in the presence of family members and close friends without written consent. If the patient is unable to object or agree, the health professional may use his/her **best judgment** to disclose health information for the best interest of the patient. Disclosure of information may be a hospital policy, not a HIPAA rule.

If you would like to learn more about HIPAA, check on line, there are several websites to choose from! Take the time to be informed.

See if you are up-to-date on you HIPAA knowledge. Take the quiz in the adjacent upper right hand column,

*Which of the following do you think is an example of Protected Health Infor- mation?		
1. Hospital Bill	Yes	No
2. Job Application	Ye s	No
3. Pharmacy prescription	Yes	No
4. Drivers License	Yes	No
5. Employee ID Badge	Yes	No
6. Any list of patient names and their respective health insurance provider	Yes	No

Answers:

I. Yes 2. No 3. Yes 4. No 5. No 6. Yes

*Sample test taken from the NYS Governor's Office of Employee Relations

http://www.goer.state.ny.us/train/onlinelearning/HIP/101.1.12.asp

Meet Deneen Shadakofsky

The Wyoming Cancer Surveillance Program welcomes our newest member to the WCSP team, Deneen Shadakofsky, April 14, 2008.

Deneen was born and raised in Wyoming with a lot of relatives still residing in the northeastern Part of the state. She moved to Cheyenne in 1987. Married to her husband Dan for almost 19 years. She has three kids, Matt is 21 and lives and works in Wright. Brandon is 17 and a junior at East High, who loves track and tennis. Danielle enjoys dance and gymnastics and is a freshman at East High.

Deneen started working for the Department of Health in the Health Facilities and Licensure division in January of 1991. Deneen continued working with the different agencies with the Department of Health until she and her family moved in the summer of 2001. Deneen recently moved back to Cheyenne last summer, where she says, "she is glad to be back and hopes to stay."

Please Visit Us

The WCSP is located at the Wyoming Department of Health within the Preventive Health and Safety Division

http://www.health.wyo.gov/PHSD/wcsp/index.html

Here you will find information about Cancer Surveillance, What's New, Links, Annual Reports and our Employee Directory

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Congratulations!!

Vicki Moxley and Julie Espinoza, Wyoming Cancer Surveillance Program, are Wyoming's newest Certified Tumor Registrars (CTR). Vicki and Julie passed the Spring, 2008 CTR exam. Great job!